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ABSTRACT

Parents (N=58) of young children with disabilities and their service providers attended 18 focus group sessions where they discussed what services they would choose if given a million dollars to spend on their own service programs. The focus groups were held in nine geographically and demographically diverse communities in Colorado, North Carolina, and Pennsylvania. Comments were grouped into the areas of family support, expansion of services, increased personnel, communications/networking, equipment, professional training, and other. Parents and service providers substantially agreed on how the money might be usefully spent, with high priority given to helping families with crisis conditions, respite care, increased use of special therapists and therapies, and increased intensity and breadth of treatment. Service providers also wanted improved billing practices, training for daycare personnel, and referral systems. Results suggest a need for a different service model, one which employs special therapists as consultants and supervisors over teams of early interventionists who will carry out many of the special therapist's current duties. (Contains 15 references.) (DB)

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The Million Dollar Question: Unmet Service Needs for Young Children with Disabilities

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Executive Summary

This paper summarizes the comments of parents of young children with disabilities, together with the comments of the service providers that work with them through eighteen focus group sessions, using a single question on what services they would choose if given a million dollars to spend on their own service programs. These focus group sessions were held in nine geographically and demographically diverse communities; three in Colorado, three in North Carolina and three in Pennsylvania as part of a larger research effort conducted by the Early Childhood Research Institute on Service Utilization (ECRI:SU). The focus group sessions were transcribed and the results to the Million Dollar question were categorized into various themes. There was substantial agreement between parents and service providers on how the money might be usefully spent. The amount of family support should be increased to help families with crisis conditions and with respite care. Also, both groups agreed that special therapists and therapies should be bought that are now in short supply. The parents were not aware of some of the systems problems that bother service providers, such as billing practices and improved referral systems. But both groups recognized the need to increase the intensity and breadth of treatment. These responses revealed some perceived major shortages and limitations of existing service systems.

The Million Dollar Question:
Unmet Service Needs for Young Children with Disabilities

How does one discover the unmet service needs of families with children with disabilities? Over a period of two decades the goal of public policy for families with a child with disabilities has been that appropriate services would be available for all children who need them. The Individuals with Disabilities Education Act (IDEA) conveyed the clear intention to provide assistance to families beginning at the birth of their child with disabilities. However, there has often been a major gulf between policy development and policy implementation (Gallagher, 1994), so it becomes important to determine the extent to which the intent of this federal law is being carried out at the local level.

The purpose of the present paper is to explore the, as yet, unmet needs of service providers and of family members through the use of focus group interviews in nine communities in three states. The nine sites consisted of North Carolina (Greensboro, Moore County, Surry County); Colorado (Boulder, Canyon City, Leadville); and Pennsylvania (Pittsburgh, Indiana, Clearfield). Separate focus groups were conducted for service providers, and for families, in each of the nine sites. This study was conducted as part of a larger program of research by the Early Childhood Research Institute on Service Utilization, ECRI: SU (Harbin & Kochanek, 1991). The current paper contains syntheses of the responses of the nine provider and nine family focus groups to a single question, 'How would you spend an extra million dollars in your service programs?'

The use of focus groups to obtain consumer preferences has been accepted as a procedure in market research, testing the attitudes of voters in political campaigns (Krueger, 1988), and seems to have multiple uses in social science research (Bertrand, Brown & Ward, 1992; Fullagar, Crotser, Gallagher & Loda, 1993). The focus group can yield a rich source of information regarding the feelings and attitudes of group members. The interactive nature of focus groups allows for the identification of a variety of issues and allows participants to build upon the responses of others who are also providers for or parents of children with disabilities (Able-Boone, Sandall, Stevens, & Frederick, 1992; Able-Boone, Sandall, Loughry, & Frederick, 1990; Summers, et al., 1990).

Focus Group Participants

The focus group participants from the families were chosen from a sample of over 230 families with children with disabilities in the nine counties. Another 72 families were chosen for individual case studies and did not participate in the focus group sessions. The focus group participants from the service providers were chosen from the roster of service providers in each of the nine sites.

The coordinators for each of the nine sites were asked to provide a list of parents who would be representative of the cultural mix in the family groups served by the programs. (Again the seventy two case study families were drawn

Table 1
Demographic Portrait
Families in Focus Groups*

Gender

Men	Women
10	35

Race

White	African Amer	Hispanic	Other
36	6	2	1

Marital Status

Single	Married	Divorced
4	40	1

Educational Level

Some High School	High School Diploma	Some College	College Degree	College +
6	7	15	11	6

Income

Below Poverty	Poverty - $20,000/yr	More than $20,000/yr
6	10	29

*Records on 13 family members unavailable.

out before the family selection was made). Similarly, the coordinators were asked to provide a list of professionals who worked with families in some capacity with an emphasis on diverse professional roles (social work, early intervention, occupational therapist, etc.).

The families were contacted and asked to volunteer for the focus group sessions and a sufficient number was obtained from each of the nine sites. Table 1 provides a demographic portrait of the families who participated in the focus groups. Judged by educational level and income, the families were predominantly middle class white mothers with a smattering of men and minority group members also participating. There were four husband and wife teams who participated in the discussions.

The service providers who responded to the request to participate in the focus groups included early interventionists, preschool teachers, support personnel (speech language pathologists, occupational therapists, physical therapists, nurses, etc.) and administrators (service coordinators, principals, etc.). The overall count of the service providers in these focus groups can be seen in Table 2. The focus group session typically lasted from one and a half hours to two hours.

Table 2
Professional Disciplines or Roles
Focus Group Participation

Discipline	N
Early Intervention	12
Pre-School Teacher	22
Special Therapies (OT, PT, SLP, etc.)	12
Administration	5
Coordinators of Service	12
Other	4
TOTAL	**67**

All personnel were women, six were minority.

Procedures

The focus groups were conducted by the author and by two other staff members of ECRI:SU. In the focus group, the participants were asked to discuss those services that they considered to be going well, as well as to express concerns about services that were not available, or were not going well. The total focus group findings are reported elsewhere (Gallagher, 1996).

The question under particular scrutiny in this paper, "The Million Dollar Question," was the last question posed to the focus group participants. Other questions in these sessions dealt with the participant's perception of services delivered and services needed, IFSP/IEPs, transitions, finances, transportation, and so on.

The "Million Dollar Question" was introduced by referring to an old TV program, *The Millionaire*, where the plot of each show involved an anonymous millionaire giving away a million dollars to a different individual each week. The basic question posed to each of the groups was as follows:

> **Suppose the (Center or Program) came into a large gift of money (one million dollars) that would allow you to do more or different things than you are able to do now. What kind of things do you believe the leaders should spend this new money on?**

This probe based on the "Million Dollar Question" never failed to stimulate considerable discussion of the unmet needs of the programs and ideas as to how those shortcomings or needs could be helped by this unexpected source of

funds. The responses to this one question were so rich that they deserved a separate presentation of results in this report.

The focus group discussions from each of the 18 focus groups were transcribed and coded for content and positive/negative responses. For the "Million Dollar Question" the responses were placed into the categories noted in Table 3.

RESULTS - THE MILLION DOLLAR QUESTION

Table 3 presents the themes that were generated by the "Million Dollar Question" by parents and by service providers in seven major categories. There were no major or consistent differences by size of community or by state in the suggested uses of the money, so the total responses of the nine communities are grouped together here. There was a strong general agreement between the two groups, service providers and parents, regarding the desirable uses of the extra funds.

The numbers opposite the major category (e.g., Family Support) represent the total number of responses in that broad theme for all focus groups. The numbers in parentheses represent the subtopic frequency. That is, Parent Education and Training was mentioned four times in the overall tally of the focus groups by service providers and two times by the parents. Family Support was the first choice of the service providers for the use of the extra money and it was the second choice of parents.

Table 3

The Million Dollar Question

Summary Themes

SERVICE PROVIDERS		PARENTS	
FAMILY SUPPORT	(16)	FAMILY SUPPORT	(11)
Parent Education and Training	(4)	Parent Education	(2)
Help Poor and Working Class Families	(5)	Help Siblings	(1)
Respite Care	(2)	Respite Care	(1)
		Help Working Poor	(1)
		Parent Support Group	(1)
EXPANSION OF SERVICES	(14)	EXPANSION OF SERVICES	(13)
Increase Range of Services (more infant programs, day care centers at worksites)	(6)	More Special Therapies (Speech, PT, etc.)	(3)
Integration with Nondisability	(2)	Increase Range of Services	(3)
INCREASE PERSONNEL	(10)	INCREASE PERSONNEL	(10)
More Special Therapists	(5)	More Special Therapists	(5)
Reduce Case Load	(2)	Reduce Case Load	(1)
Staff for Family Support	(1)	More Case Managers	(1)
Classroom Aides	(1)	More Teacher Aides	(1)
COMMUNICATIONS/NETWORK	(9)	COMMUNICATIONS/NETWORK	(2)
Community Awareness	(2)	Community Awareness	(2)

SERVICE PROVIDERS		PARENTS	
Better Telephone Services (Pagers)	(3)		
Simultaneous Staff/Family Training	(1)		
Bilingual Staff	(2)		
EQUIPMENT	(8)	EQUIPMENT	(2)
Playground and Toys	(2)	Therapy Equipment	(2)
Computers	(2)		
Materials to Leave Families	(1)		
More Therapy Equipment	(1)		
PROFESSIONAL TRAINING	(6)	PROFESSIONAL TRAINING	(1)
Educate Day Care Personnel	(4)	Re-Educate Social Workers	(1)
Released Time for Conferences	(1)		
OTHER		OTHER	
Increase Salaries	(4)	Increase Salaries	(2)
Inclusive Programs	(4)	Inclusive Programs	(2)
Transportation	(3)	Transportation	(0)
Consumable Supplies	(2)	Consumable Supplies	(1)
Referral System	(2)	Referral System	(2)
Reserve Fund	(1)	Improve Medical Services	(3)

Parents - Family Support. The parents had a variety of things to suggest, from the establishment of parent support groups, to parent education, to help for the siblings of the child with disabilities. Some of the direct statements by parents follow:

> **"I would take part of the money and figure out a way to have subsidized respite care to the point where you would feel like this money was set aside for you, and if you don't spend it, you lose it. So you would feel less guilty, less reluctant to have someone come and take care of our child. Sort of force us to get out of the house and go do something for ourselves."**
>
> **"... to actually sit with the baby. Show them how to talk to their infant more. How to stimulate the infant, how to read to their preschoolers, how to look at the picture, how to hold the book."**
>
> **"....go in and train parents in parenting one-on-one in their home."**
>
> **"It would be nice to have like a place where parents could just go and be with other parents. And be able to talk among themselves and give them time to learn from other people, rather than just dealing with their own kids..."**

Service Providers - Family Support. In particular, the service providers were eager to use more resources to help poor and working class families and provide additional parent education and training. Some of the service providers' suggestions were as follows:

> **"Some should be spent on parent education. Making sure that there is all sorts of funds that parents have access to provide education."**
>
> **"As a social worker I believe strongly that if you don't meet the family's basic needs, you're not going to move from there."**

"I've got one. I would like to see the families have their basic needs met. They've got food on the table, they've got good health care, so they can focus on the child instead of being so tied up in just surviving."

"Besides the obvious therapists that we need, I would like money to provide telephone services to our families. Whether it's a huge party line or several, or something, so that we can reach them, they can reach us."

"Maybe, maybe even help, like get parent advocate or parent support groups started in different areas so that parents who live out in different outlying areas from where the normal centers are that they could feel like they have something to contribute and it's not forever to get there."

"I would spend it on respite care for families."

Parents - Expansion of Services. The parents and service providers both wanted a wide variety of additional services, often specialized services that were not currently available or were in short supply.

"And maybe more speech therapy, because like right now we can't afford more therapy, you know, because you have to pay by visit."

"I think that (*extended care from 3 p.m. to 5 p.m.*) would be wonderful to be able to do that somehow. So many parents need that, and then the child could be in one site. We find it so hard for kids to go to different places."

"And there could be services available for extended families."

"And too, there needs to be facilities out here to where they have nurses and health care providers, like in a daycare or something, so that parents, like single parents who have children who are disabled can go to work, whether they be a newborn on up."

"And I think the care needs to extend....but nobody comes to the house, and to, and sees him in the environment and sees the behaviors at the house."

"Full-year school for these kids."

"Then I would hire a person whose job it was when you have a home that is not in deep trouble, but Mom just has a little trouble keeping the laundry done or you know, those kinds of things. That person would go into that home and help Mom get her act together. Or, you know those kinds of services."

"I think provision of different models too. That there is a choice. There truly is a range of service, so that not every program or every whatever is going to suit every family."

Service Providers - Expansion of Services. The service providers were also eager to support specialized services and some other ideas as well.

"And wouldn't it be neat if you could pay your staff a decent salary so that we didn't have turnover, which is very, very....but yeah. It's very hard for children to have lots and lots of turnover, and that's a critical problem in early childhood."

"More therapists would make it easier to schedule and family, more family friendly, maybe. To get, to be able to work around better scheduling."

"I think more dollars for therapy in general. So that you guys aren't spread as thin as thin can be."

"We would want to spend it right now on integration. Having more peer models, you know, we really feel that's a need. Scholarship money, something like that. For the typical kids to be in our program...."

"As long as we're coming up with really creative things, I think it would be great if we had daycares set up at worksites so that family members could go in and out of daycare and have like half-day jobs and transitional jobs so that they would not have to be so divorced from their child's growth period."

Parents - Increase Personnel. Closely related to the service expansion was the desire to increase the number and type of personnel. The parents wanted

the agencies to hire more specialists in the special therapies and more teacher aides and to reduce case load. The service providers agreed with the parents in the need for more special therapists and a reduction in the case load. Both groups see the limited professional skills of the current professional staff and want the staff expanded. Unfortunately, a separate policy study (Yoder, Coleman, & Gallagher, 1992) has reported a serious and continuing shortage of personnel in the very areas that are being asked for by professionals and parents: occupational therapy, physical therapy, and speech therapy (see Discussion).

> **"More speech therapists."**
>
> **"Yeah. More speech therapy."**
>
> **"We need a better pediatrician. The fact that we can bring in the money to get a good special needs pediatrician, or even one who was just plain good, who cares."**
>
> **"Yeah, but I think bringing the specialists into the area. Because we want these kids in these programs. We don't want to have to ship them to a private school. We want them to be in their neighborhoods and so, anything they can do to help with that. More therapists."**
>
> **"They need to hire more teachers, too. Specialized teachers."**

Service Providers - Increase Personnel. The service provider comments reflected the heavy case load and the need for some relief.

> **"We'd like more days of the week for the kids. We'd like to be able to offer a variety, you know, if people only want to come three, fine, but if they'd like to come five, I'd like to be able to offer that. I'd like to be able to offer extended day care in the afternoon, if people wanted that. That would be wonderful."**

"...just the monies available to attract a person who would stay in the area for the time."

"I would put it in family support, because we had 60 families when we started, and we have 270 now. Our funding hasn't changed."

"I think I would hire a couple more therapists."

Parents - Other Comments. The parents had only a few other miscellaneous comments to make on the need for better medical services. They did not pay attention to the systems components that often preoccupied the service providers.

"Information centers to get the word out on diseases or give you information as to what to expect."

"Probably transportation (*agreement*). Transportation's a big problem."

Service Providers - Other Comments. The professional staff also saw the need for other additions that fit into the more effective use of materials and systems. The professionals want a more effective communication system within the service program so that those therapists who are on the road can communicate back to home base and save wasted hours in travel. The call of service providers for community awareness apparently comes from a need to inform the general public on the nature of the services being provided and to obtain more direct public support for their efforts. Other interview data from community leaders in the nine communities under study confirmed the general lack of awareness of these programs by the political leaders.

Items such as more equipment, better transportation and professional training are other desires of the professionals, as well as increases in salaries. Programs for infants and toddlers are notorious for low staff salaries. There is also a shortage of child care programs, which leaves few options for the parent of a child with disabilities to select from in terms of inclusive services.

> **"I'd say along the lines of training, I think there's a great need for training of preschool and child care providers together that have traditionally served the typical population and bring in early intervention."**
>
> **"I'd go program funded for sure. Scrap the billing system and go to a program funded system with big program funds, so we can purchase the therapists."**
>
> **"Probably with family support too, or a portion of it, yeah. It just seems over the years the population, I think, changes. And their needs differ, and in the past five years, I'd say, I've had more parents, when we're talking about inclusion, wanting preschool sites that are included for their children."**
>
> **"I would like to have some type of pager system, because I get cancellations, and I'm going clear to Penrose or... for a cancellation, and I could put in another kid or attempt it."**

DISCUSSION

In summary, these responses would suggest that there were two major needs agreed upon by parents and professionals. First, there was agreement that ways should be found to increase the amount of family support that we are now providing, and that includes helping families with crisis situations and respite care. The point was often made that families who are in crisis mode over food and shelter often don't have time for the care of their child with disabilities (Dunst, Johanson, Trivette & Hamby, 1991).

Second, both parents and professionals identified the need for special therapies and therapists (OT, PT, Speech, etc.) that are now in short supply. The special services that are available are limited, delivered in brief periods, and have high case loads. There is some concern that the limited intensity of treatment was not enough to make a difference.

The desire for more skilled personnel is easily understandable, but the other information we have about the chronic shortages of such personnel (Yoder, Coleman, & Gallagher, 1990) should cause us to consider a revision of the current service delivery system. The brutal truth of the matter is that there are not enough special therapists to go around and this is not a situation that will be corrected in the foreseeable future, regardless of the availability of funds.

Under such circumstances, some thought needs to be given to a different service model employing the special therapists as consultants and supervisors over teams of early interventionists who could carry out much of the special

therapist's duties under instruction and supervision. This would require a restructuring of the therapeutic landscape, but there seem to be few options to the above idea unless one settles for the fact that many children with disabilities will not get needed care or special education regardless of what the law or regulations promise (Walker, 1992).

The parents do not seem aware of some of the system and communication needs that bother the professionals (e.g., service providers worry about billing practices, training for daycare personnel, improved referral systems, etc.). The parents have basically centered their hopes on more direct help for the family and more trained personnel to work with their child. The responses to this "Million Dollar Question" were thoughtful and did not contain merely a 'give me more of everything' attitude.

The responses of both service providers and parents showed a recognition of the need to increase the intensity and breadth of treatment if additional resources were available. The analogy of diluting penicillin from the required 50 mgs. to 5 mgs. to make sure everyone gets some hits home to the service personnel who wonder if the small amount of time doled out to each client provides worthwhile service.

In this regard, The Million Dollar question proved most enlightening. There is not always a gentleman in a derby hat just around the corner willing to write a check for an extra million for our deserving programs. The process of

pretending there is, though, allows us to think about alternatives for service delivery that can provide better services for the families that we care about.

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